



## The Autumn/Winter Review - February 2015

**A regular seasonal round-up of all things that seem important.**

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**1. Caring in the Community:** In the first year of the project – it seems a long time ago – community projects were often viewed as a way of cutting costs by getting volunteers to “do the work” instead of paying professionals. A year or so later the Government suggested that the “Big Society” would create an army of volunteers to provide the time and money needed to meet the projected shortfall in health and social care funding. We resisted this by saying that we were not about “helping the County Council to meet its budget” but rather to work with the professionals on the ground to provide a new model of care provision. We realised then that there is a critical dimension of dementia care which cannot be provided by remote clinics and services. Families who are having to cope with the impact of

dementia on their lives need to be supported by knowing that their community “cares” – that despite their feeling alone, there are so many friends and neighbours who understand what they are going through and want to be “there for them”. This is not something that the statutory authorities can provide, yet it is probably the most important element of support in a family carer’s life. The Debenham Project places great emphasis on supporting the carer and cared-for together, and on recognising that the primary determinant of quality of life lies in maintaining family, social, and community relationships – “Interaction is the chemotherapy of dementia” (Henry Simmons of Alzheimer’s Scotland). So we hope that the project has become not simply a service or a set of clubs / activities but a “family” in which friendships are made and in which we can always turn to each other for support when we need it.

So, I have been especially heartened recently to see the way that the whole direction of the dementia care sector has become focused on local provision of diagnosis and support, and on trying to encourage more and more communities to become not only “dementia friendly”, but to become “dementia pro-active” by setting up cafes, information and advice facilities, activities, support groups, clubs, etc – by “getting on and doing something”. There is a long way to go before quality help and support for family carers, and those they care for, is “just a step away” and available in all our towns and rural communities, but it has started. As one of the earliest community-based projects we are doing what we can to help it happen and are involved in efforts to encourage new projects to start up in partnership with charities, the local authorities and the NHS. It is our hope that Suffolk will develop a coherent funding strategy to give individuals and communities the confidence to make that first step knowing that their success will be rewarded by a “sympathetic bank manager” investing in their goodwill and motivation.

**2. The “Confidential Telephone Helpline” closes:** Over 5 years ago The Debenham Project was publicly launched and one of the first services was a confidential telephone line operating in the evenings at weekends (Fri/Sat/Sun).

Each weekend evening, without fail, a volunteer was at the end of the line to offer a listening and understanding ear for any family carer who might be reaching the end of their tether. There may have been only a limited number of calls in that time, but that did not affect the value of the service. Whenever we asked family carers, they repeatedly said that it was important to know that there was someone local there “in case” - an insurance against the time of a crisis.

Today, the Suffolk Dementia Helpline (01473 353350) provides on a county-wide basis excellent and caring support to all who make contact. So it was decided that the time had come to close the Debenham Project’s helpline. However, anyone local who calls the Debenham Project’s number will automatically come through to “Bleak House” and we will always respond.

Over 5 years the helpline team “were there” for family carers over 750 times. It has been the sort of special commitment that deserves all our gratitude.

**3. Why do so many do so much?** A while ago a lady from AgeUK Suffolk came to interview me for an article in their "Choices" magazine. After talking about the project for some time she suddenly asked me "why do you do it?" She asked whether it was because my mother had dementia, or was it that I saw the massive need. I replied that I didn't really know - both might be true but only partly so and, even then, perhaps only in the early days. Now, I think that it is mostly because through being a part of The Debenham Project I see the best in people, I see them helping to make someone else's life just a little bit better, I see friendships forming and old friendships renewed, I see lots of laughter (and chocolate cake!), I see genuine and unconditional caring, and I see that it "makes a difference". It gives me moments of joy and makes me feel good to be a part of it. That is probably why I, and so many others, "do it".

I also see how important community-based projects are in the overall scheme of things. Certainly, it is important for us to recognise that statistics are vital in evaluating the cost effectiveness of what we do – after all it is only through the funding by the local authorities, the NHS, charitable foundations, and individual local donors – and this must be accounted for - that we have the money to sustain The Debenham Project. However, perhaps because ours is a small local charity, I see what really motivates our volunteers are the small things - in a conversation with a carer or the person they care for, the atmosphere in one of our activities, the thanks for a lovely time, etc. - which show that their commitment is more than worthwhile and that it is indeed making a difference.

**4. National Recognition for The Debenham Project:** Some time ago one of our High School Students, Rosie Voller, nominated The Debenham Project for an award, given each day by the Prime Minister, recognising the contributions that volunteers are making in the community. I was delighted to hear that I had been given the Prime Minister's "Point of Light" award for the 21st October and was congratulated in a personal letter from David Cameron. Thank you so much for all your help in achieving this - as I said in my letter of thanks to the Prime Minister:

" It has been my privilege to be a part of The Debenham Project and to experience, not only, the genuine and unconditional care and support given to local families who are living with dementia by our volunteers, but also the tremendous goodwill and support provided to the project by our local politicians, the local authorities, the NHS, the established charities and many others in the community. This is also their award."

However, like London buses, another award for the project came along at the same time. This was an "Inspiring Age Award 2014" from Age UK Suffolk in recognition of our contribution to the community. Whilst I know we don't seek praise for what we do, nonetheless it is great to know that our efforts are held up as an example of what can be achieved.

**5. Christmas and the New Year:** I do hope you all had a lovely Christmas and

New Year. Of course, Christmas is for most of us a lovely, if a bit hectic, time. However, too often for family carers, making it a special occasion is not easy – and sometimes family celebrations can be very difficult if the person they care for has symptoms that are more than “just a few memory problems”. I would just like to say a big thank you to everyone who helped to make the lunch clubs, Carers Club & Info Café, CAMEO and Fit Club so seasonal and so festive for those who participate. Whatever we can do to help them feel included and a part of all the seasonal enjoyment means a lot. Therefore, as usual we added something special into our diary of activities and clubs - “The Music Man” (Stephen McKie) with our "Merry Christmas Musical Extravaganza and Sing Along" at the Carers Club. It was a very memorable occasion in which there was so much involvement, joining-in, laughter, appreciation, friendship, and of course luscious cakes that only one word can describe – “Wicked”.

I have seen the effect of music and singing on the spirits and well-being of participants many times, and many of our families have memories of the tremendous value of it during the Second War. I should not be surprised, but it always makes me wonder why it is that we cannot view such “therapies” as **mainstream** treatments which are as beneficial for those with dementia (and their families) as medications are to those with other illnesses.

**6. A unique way of evaluating achievement:** Before Christmas “cometh” Advent – the period in the Church calendar that runs from the end of November through to Christmas week. Our tireless rector, Patrick, suggested that on this occasion the church might be used to inform local people and visitors about the various local charities and community activities in Debenham. His idea was for a novel form of information display – “The Charitree” – a sort of Christmas tree but designed to capture the essence of a charity in a novel and artistic way. On behalf of The Debenham Project I want to express my thanks to Sue Holifield (and her husband Colin), Margaret Denny, and Sally and Rex Garrod for our delightful and expressive display.

When I was admiring it, I was struck by the fact that it represented a unique and attractive way of showing something of what the project means to those who participate in it, and what it has achieved - what the local authorities and the NHS call “project evaluation” – what we call “how we are doing” and “has it been worth it”. For those who did not get a chance to see the exhibit you can see it on the web site and read some of the comments that family carers and those they care for have made.

**7. Our third lunch club opens:** I am delighted that Janice Romaniszyn, with Françoise Behar and Kate Robbins started a third Food ‘n’ Friends lunch club and had their first lunch at the end of November. These lunch clubs are greatly appreciated by all who participate and we still have a waiting list of potential guests. However finding organisers/hosts has not proved so easy. It isn’t a great commitment – just once a month – if you can offer to help, that would be wonderful. We would dearly love to be able to host a fourth club this year. I believe that Food ‘n’ Friends is an

excellent example of how we can befriend families struggling with the problems that dementia presents, in a simple way that just makes a pleasant occasion now again and reinforces that they are not alone.

## **8. Best wishes to a great friend, and welcome to a new carers support**

**service:** Suffolk Family Carers was a pioneer in raising awareness of the plight of family carers many years ago, and in developing support services for all. Jacqui Martin co-founded the charity and was its chief executive until she “retired” at the end of last year. Jacqui has been a great friend and inspiration to The Debenham Project, but much more importantly, a great friend to all family carers, never losing the desire for personal contact with those her charity is helping.

It was great that in her final year, Suffolk Family Carers so successfully raised the money for, bought, equipped, and staffed the “**Suffolk Family Carers Bus**”. I am sure many of you helped with donations for this major project. Now it is delivering the fruit of so much effort, and the bus is touring the county offering advice, information, support, therapies, etc in our rural towns and villages – It came to Debenham early in February and I hope that it will become a regular visitor over the coming months and years.

I wish her all that is best for the future – and thank her for all she has achieved for every family carer in Suffolk who is struggling to “manage” and “keep it together”.

**9. Where does the money come from:** A little while ago a volunteer mentioned to me a conversation that she had had with someone who thought that our informal transport network was a free service (actually we only charge our volunteers’ expenses). When asked why she thought that, the response was that “The Debenham Project has lots of money – Lynden is always thanking people for their generous donations”! How I wish that that was true. However, she raises a valid question about how small charities such as ours “balance the books”.

Broadly, in order to keep the project running, we need to find between £8,000 and £9,000 each year, and we need to build up our reserves for the “lean years” and for the development of our work. Our overriding requirement is to keep the “current account” out of the red. So, what do we spend our income on? Firstly there are the fixed costs which are things like insurance, room hire, telephone and broadband, printing and stationery, postage, capital equipment and services, and other project management costs. This amounts to about half of our budget. Secondly, there are the variable costs (although in practice we would have to give up one or more of our services in order to reduce costs). These are all about covering the expenses of our various activities, clubs and services such as transport, CRB/DBS checks, special events, travel, Fit Club instructor, cakes for the Carers Club and Info Café, outings, materials and equipment, etc. These represent the other half of the budget.

Where does our income come from in order to pay for these? It comes from a variety of sources:

Firstly, there are the individual private donations that are quietly given. For example this Christmas there was a knock at our door and with an “I’m sorry that we can’t be directly involved in the project but I hope that this will help”, and a donation, with gift aid, amounting to £750 was handed to me. This was exceptional in its monetary value but equally important are the many smaller sums like the envelope containing £25 anonymously pushed through my door. We even have a lady who regularly donates from Sweden.

Secondly, we are helped by fund-raising by groups and organisations that put on functions such as an organ recital, a music event, or a concert; others that have made the project their chosen charity; a pub quiz team; giving through the Co-op divvy; and Debenham’s Pop-Up Department Store.

Fourthly, although we try to follow the aims of the NHS for our services to be “free at the point of contact” we do ask for small contributions from participants in our lunch clubs, Fit Club, Cameo, and transport service to offset some of the costs and expenses.

Thirdly, there are the donations made by the families and friends in memory of someone who was part of the project but has since died – and even of people such as Ken Dunnett who although not directly involved in our work held it in high regard.

Finally, we receive funding through grants and awards that we have to apply for. It can take a lot of time and effort and competition is great but it is totally necessary if we are to match our income to our outgoings. Over the years we have been fortunate to benefit from funds set up by Mid Suffolk, AXA, Sports Relief, Suffolk County Council, Waitrose, Comic Relief and others. The Suffolk Community Foundation which manages many of these funds has been a good friend to us.

So it should be no surprise that I am so grateful for all these contributions which, together, have kept the Debenham project, not only in business, but also able to continually develop and improve its services. However, for all small (and larger) charities, fund raising represents a substantial overhead and a distraction from “getting on with the job”. Is there a better way? For community-led organisations like The Debenham Project we believe that there is, and that is why we are seeking to persuade the Social Services and the NHS to develop a coherent funding strategy that will at least provide financial security for successful projects, and also encourage other communities to initiate their own projects. I am very pleased to hear that steps are being taken to look at the latter.

**10. Influencing the future of care:** In last year’s summer review, I reported on the research that we had conducted which sought to explore an innovative approach to the provision of health, social and housing care for frail elderly people in our community. Although we in Debenham set up the Debenham Project specifically to provide support for those in our area who were coping with the impact of dementia on their lives, it was always recognized that this was just one, albeit major,

aspect of the problems that an ageing population will create for communities like ours. The result of our research was a model of care which turned the historical top-down emphasis of the NHS upside down. When it comes to providing health and social care for the frail elderly, the curative model (“we can make you well again”) does not match the fundamental nature of the problems generally associated with becoming elderly and frail. What is needed is something closer to the palliative model (“we can make your quality of life better”) and this involves taking a bottom-up holistic community-based approach. Hence, “The Vision of Caring”. It is no secret that we would like to put these ideas into practice in the Debenham area – to provide an exemplar of the best that can be provided in caring for those who need help to live as full a life as possible despite their illnesses and frailties. Just to persuade the local authorities, the NHS, and other decision makers to give their support to a pilot will be difficult - to “put it all together” even more so. However, “you can’t succeed unless you start in the first place”. At the very least, we must try to influence the “direction of travel” of health and social care in favour of being locally-based, person-centred, and community-led. I like to think that what has already been achieved in Debenham has made a contribution to the way that dementia care is developing in the county and perhaps nationally, so I hope that it isn’t quite out of the question that our research will be taken seriously by those who are responsible for defining the future of care for the frail elderly. To that end I have recently been in conversation with Prof. John Young (Clinical Director for Frail Elderly for NHS England) and he has offered to visit us together with Alistair Burns (National Dementia Tsar) to take part in a special workshop to discuss the issues.

This review is just a snapshot of what has been going on in The Debenham Project over recent months:

**Just a regular seasonal round-up of all things that seem important.**

Please don’t hesitate to contact me on 01728 862003 if you want to know more about any of the items. You can also get more information by visiting our website at [www.the-debenham-project.org.uk](http://www.the-debenham-project.org.uk) .



With my very best wishes

Lynden Jackson (Chairman)